

A Question of Terminology

Question

A physician studies the prevalence among his patients of a common condition that is receiving attention in the popular media. He finds that the distribution of the condition among ethnic groups differs from that previously reported and does not seem attributable to the demographics of the population he is studying. The physician therefore believes that his finding would be useful to others and wishes to publish it. However, the commonly used US Census Bureau designations “American Indian or Alaskan Native”, “Asian or Pacific Islander”, “Black, not of Hispanic origin”, “Hispanic”, “White, not of Hispanic origin”, and “Other or Unknown” are not sufficiently specific to describe at least 2 subpopulations of the affected patients—one in which all appear to have Irish surnames and another in which all are of Caribbean origin. The physician consults you, an editor, about how to proceed.

Solutions

The Census Bureau designations for labeling subpopulations are inadequate for the physician's purpose, and it is most unlikely that the Census Bureau will change its designations solely to suit a single physician-author's needs. The editor should ask the physician whether communicating his findings accurately warrants noting the ethnic characteristics in the first place. If so, the physician should use the phrases in the question—“Irish surnames” and “Caribbean origin”. Those phrases are wholly descriptive and objective; they are not inherently offensive. In using them, the physician will not be suggesting any other characteristics, good or bad, but might well be conveying information that will be useful to later researchers.

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Terminology in ethnicity and health research has been much debated in recent years (1-5). Literature in this field has been weakened by the diverse, sometimes idiosyncratic, definitions and terms used to describe study populations. Terms must be defined appropriately both for understanding the reported research and for comparing studies, particularly internationally. However, the number of studies that actually provide such definitions is small.

In this example, the physician's approach should include the following steps:

- 1) The physician should refer to the large literature on how to handle ethnicity and race (2-5).
- 2) The physician should refer to the British Medical Journal guidelines (1).
- 3) The physician should describe the demographic, socioeconomic, and cultural characteristics of the population fully.
- 4) From these data, the physician should create a rational textual description of the ethnic groups (built, if possible, on existing classifications) and should explain what has been done. Then an appropriate label can be attached to summarize the description.
- 5) The physician should not readily rule out socioeconomic factors as the key explanation for group differences.

Identifying ethnic subgroups in the “white” population is also a problem awaiting answers. Names are likely to be an inaccurate way of ascribing Irish ethnicity.

As this example shows, there is an urgent need for a discussion on terminology by journals if a consensus is to be reached and if confusion and misrepresentation are to be avoided. Journals need to participate in debates on the nature, value, and presentation of race and ethnicity research to enhance the scientific quality of published research on race and ethnicity and stimulate researchers to sharpen their definitions and methods.

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2. Senior PA, Bhopal R. Ethnicity as a variable in epidemiological research. *BMJ* 1994;309:327-30.
3. Hahn RA. The state of federal health statistics on racial and ethnic groups. *JAMA* 1992;267:268-71.
4. Hahn RA, Stroup DF. Race and ethnicity in public health surveillance; criteria for the scientific use of social categories. *Public Health Rep* 1994;109:7-15.
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The first question I would ask the physician would be why he believes the findings would be useful to others. By explicitly stating hypotheses that might explain the differential distribution of the condition and examining these hypotheses to the extent possible with available data, the researcher may spur others on to further exploration. As recommended by the British Medical Journal (BMJ) in 1996, “authors should describe in their methods section the logic behind their ‘ethnic’ groupings” (1). As in any research, the physician should make clear the purpose of identifying “race” or ethnicity, should examine potential causes of associations as fully as possible, and should state data limitations for adequate classification and measurement of “race” and ethnicity variables.

I would make sure that the physician and other contributors are aware of the new minimal categories for federal report-

ing of “race”. The US Office of Management and Budget (OMB) has established the following categories for “race”, which as of 29 October 1997 are the basis for comparability with the census and other government datasets: “American Indian or Alaska Native”, “Asian”, “Black or African American”, “Native Hawaiian or Other Pacific Islander”, and “White”. The terminology has changed for the ethnic categories now described as “Hispanic or Latino” and “Not Hispanic or Latino”.

The observation that one subpopulation in the physician’s study shares Irish surnames might justify the assumption that the majority of this group are “White”. Without allowing for self-identification of “race” and ethnicity, however, the researcher might overlook “racial” and socioeconomic diversity within this group. Additional measures of income or socioeconomic status for areas of residence would be helpful, as would measures of diet or health behaviors that might be influenced by cultural background. Data assumptions and limitations should be stated clearly.

Finally, I would advise the physician to be as explicit and descriptive as possible about the populations being studied. “Caribbean origin” does not correspond to any of the OMB categories of “race” or ethnicity; this group should be described in terms of available information that might be relevant to exposures for the condition

being studied (or access to care for diagnosis and treatment of that condition). The 1996 BMJ recommendations on terminology provide examples that should be useful to the physician: “For example, ‘black’ as a group description is less accurate than ‘self assigned as black Caribbean (Office of Population Censuses and surveys category)’ and ‘Asian’ less accurate than ‘UK born individuals of Indian ancestry’ or ‘French born individuals of Vietnamese ancestry’.”

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New Question: A Question of Patient Consent

A manuscript you are editing as an institutional editor contains a group photograph of patients receiving treatment within a group neurology session, all of whom have signed a release for publication of the group photograph in a research article. However, the narrative of the report describes specific symptoms of several of the patients

depicted, none of whom has seen the text. The author did not obtain consent for use of this narrative and would now find it difficult to track down the patients. You ask a representative of the institutional review board whether consent is necessary for use of the narrative. You are asked in turn whether the narrative compromises patient confidentiality any more than other case reports that have been published by your institution; the board representative will follow your judgment. What other knowledgeable persons or resources might you call on to resolve your own concern about submitting the manuscript without having signed consent of the potentially identifiable patients from the group session?

The situations described as New Questions in this column are not necessarily based on actual situations, and the ones that are may have been modified to focus the question. Send your responses to the new question to Della Mundy, Kaiser Foundation Research Institute, Department of Medical Editing, 1800 Harrison Street, 16th Floor, Oakland CA 94612-3429; telephone 510-987-3573; fax 510-873-5131; e-mail della.mundy@ncal.kaiperm.org.